

Handout #1:
A Breast Cancer Story:
“Breast Cancer as I Lived It”
by Mary Scanlon

I can still recall waking up in the middle of the night and having pain in my left breast. I felt a lump as big as a quarter. It scared the life out of me.

When I got up the next morning, I went to work as usual but I called my doctor right away. He said the fact that I had pain was a good sign and that I shouldn't worry.

He said to come in to see him immediately, which I did. He examined me and then ordered a mammogram. He called me at work a few days later after the mammogram had been read at one of the top hospitals in Boston. He told me I had a tumor. He urged me to call Dr. Susan Love, who is the advocate of the lumpectomy. I called, but I was told I would have to wait *6 months* to see her. I called my doctor back, and he advised me to call her partner. I did that but still had to wait a few weeks for an appointment.

That few weeks seemed like months. The wait was agonizing. The day finally came, and she examined me. A few days later she did a biopsy. More days went by waiting for the results of the biopsy. When she called me with the biopsy results, she asked me to come in for an office visit to discuss my options. She told me to bring my husband.

Throughout this whole ordeal, I felt anxious and ignorant. My doctor told me it wasn't good news, but, if it was any relief to me, the cancer was detected at an early stage, and maybe the outlook would be good. She then told me I had a choice of a mastectomy or lumpectomy with 8 weeks of radiation therapy. She told me and my husband that, in my case, the results would be the same either way.

Again, I had to wait, this time for operating time on an outpatient basis. So I had the lumpectomy 10 days later. I was home recovering when my doctor called with more bad news. I had nine positive nodes, which meant that I had to have 4 months of chemotherapy! I hung up the phone and cried.

My doctor set up an appointment for me with an oncologist (cancer specialist). She was very nice and caring, but I was stressed out with this ordeal. I had a lot of blood tests done and then a schedule was set up for my chemotherapy.

I had to go to the hospital four times a month; I drove myself each time. I had some nausea after the treatment, but the feeling of always being very, very tired was worse. My body was wiped out by these strong drugs. I didn't have the energy I was used to; everything I did was an effort. Many days, the tiredness was too much. Still, I forced myself each day to get out of bed and go to work. At least by the end of the day, it made me feel good that I had given back something to society.

I worked at not feeling sorry for myself, but I did keep thinking, Why me? I had tried to eat healthy and exercise, and I had never smoked. Then I read a book called *Love, Medicine, and Miracles* by Bernie Seigal, and it was like reading my own story. He said that women who get this disease are sometimes the type who are always worrying about and caring for other people instead of taking care of themselves.

My faith helped me a great deal in getting through this hard time. The good Lord gave me courage and strength. My friends and family helped and supported me. I had one incredible friend who would cook a fancy meal for me the night before each time I went for chemotherapy.

I have most of my energy and strength back now. I always felt, deep in my heart, that everything would work out fine. I would like somehow to help other women cope with this dreaded disease. I learned a lot from the experiences. Having cancer taught me to open my eyes and be thankful for each day.

Handout #2: Sources for Cancer Information

National Cancer Institute, Cancer Information Service

Call 1-800-4-CANCER or 1-800-422-6237 to speak with a cancer information specialist in English or Spanish.

American Cancer Society

Call 1-800-ACS-2345 or 1-800-227-2345 to order *Cancer Facts & Figures* as well as for cancer information.

Cancer Facts & Figures is published on an annual basis. This publication is a summary of the general effect of cancer in the United States and provides summaries on the incidence, deaths, signs and symptoms, risk factors, early detection, treatment, and survival statistics for the major cancers.

National Alliance of Breast Cancer Organizations

Call 1-800-719-9154 for information or to order brochures and fact sheets.

The Susan G. Komen Breast Cancer Foundation

Call 1-800-IM-AWARE or 1-800-462-9273 for information or to order brochures.

Y-ME National Breast Cancer Organization

Call 1-800-221-2141 for information or to order brochures.

Handout #3: Barriers to Breast and Cervical Cancer Screening

Economic Barriers

- Poverty
- No health insurance; inability to pay out of pocket
- Insurance will not cover screening not recommended by doctor

Structural Barriers

- Lack of doctor's recommendation
- No health insurance
- Limited access to care sites
- Long waits at care sites
- Unfair treatment based on race, income, religion, age, sex, or sexual orientation
- Lack of transportation
- Unable to take time off from job for screening appointment
- Lack of care for children, elderly parents, or spouses
- Lack of continuity of care or a doctor reminder system
- Poor program administration
- Inadequate or no translation services
- Lack of telephone or frequent changes of address

Informational Barriers

- Lack of doctor's recommendation or referral
- Lack of knowledge about risk factors and symptoms
- Lack of knowledge about screening tests (i.e., Pap tests and mammography)
- Lack of opportunities for patient education
- Lack of exposure to language- and literacy-appropriate reading materials and media coverage

Cultural and Individual Barriers

- Lack of doctor's recommendation or referral
- Beliefs and customs regarding health care, preventive care, and screening. This includes not seeking care when there are no problems or symptoms
- Past experience with health care systems that did not offer preventive care or screening
- Beliefs and customs about self-care and ability to effect change in health status
- Fear and anxiety
- Fatalism (an attitude or belief that cancer is God's will or fate and cannot be changed)

- Desire not to know if cancer is present
- Issues of privacy, embarrassment, dignity (e.g., telling personal or family information, disrobing)
- History of sexual abuse
- Procrastination (putting off or avoidance of doing something that needs to be done)
- Fear and distrust of Western medical practices and doctors

Adapted from Goldman, R. Barriers to breast and cervical cancer screening. In Dubé, C.; Rosen, R.; Goldman, R.; Ehrich, B.; Toohey, H.; Rakowski, B.; Goldstein, N. Communication skills for breast and cervical cancer screening: a medical school curriculum. Providence, RI: Brown University; 1998. Permission for additional reproduction, beyond normal classroom use, must be obtained from the author or principal investigator, Catherine Dubé.

Handout #4:
A Cervical Cancer Story:
“My Life Story With Cancer”
by Mary Walker

When I was in my early twenties, the only time I went to the doctor was when something was hurting me or when somebody made me go. I hated the doctors. When I got older, I felt I should start getting checkups.

Everything was going fine until one day I started having pain in my stomach. I thought it would go away, so I ignored it. All of a sudden, the pain started coming more and more each month. I knew something was wrong, so I started going to the doctor more and more. He did test after test. All of a sudden, he came up with something. The test showed I had cervical cancer.

When he told me that, I could not believe it. No one in my family had cancer. I said to myself, “Why me?” I worried most about the surgery. I thought they would put me to sleep and I wouldn’t wake up. But I knew I had to have the operation.

I think it scared my mother more than me. The doctor explained to me what he was going to do, but I was upset. I only half-listened to what he said about the surgery. The nurses wanted me to walk around to get my strength, but I didn’t want to be bothered. When I’m in pain, I don’t want to have anyone hovering over me.

I’m the strongest one in my family; I think that’s why it happened to me instead of someone else in my family. I don’t think they could handle it as well as I did!

The first surgery was a scraping. The second test was a cone biopsy. I thought everything was fine. It was—for a little while.

All of a sudden, one day I started hurting again. I went back to the doctor. He did more tests and said I had to have a hysterectomy. I said, “No way.” I gave him a hard time for a long time. My family wanted me to have the hysterectomy so I wouldn’t have any more pain. I felt I was too young, and most of all I always wanted a baby.

I was giving up my chance of having the family I always wanted. I cried every night. I was heartbroken. I put off the surgery. One day, I was not feeling good, so I went back to the doctor. He took tests and found out I was pregnant. I was surprised and happy, but it was not good news. I had a tubular pregnancy and cancer on the same tube. I was finally going to have the baby I always wanted, and cancer came along and took it away. I was admitted that same day for surgery. I cried all day and all night. My hope for a family was gone.

I felt like I was less than a woman. I felt that no man would want anything to do with me once he found out I couldn’t have children. But my friends and family told me that having a baby doesn’t make a woman. To me, a woman is a person who respects herself and loves others.

The only thing I could remember after my surgery was waking up in lots of pain. After the anesthetic wore off and I knew it was all over, I was hurt and sad. I didn't want to talk to anyone. My mother's friend came to visit me; I wouldn't even talk to her. The nurse wanted me to get out of bed and walk around to get my strength back. I didn't want my strength back. I didn't care what happened. So I stayed in bed the whole week, except to go to the bathroom. I didn't eat. I cried all the time, even after I got home.

When I got home, friends and family came to see me all the time. Without their support, I don't think I could have made it through that. Every day, I got my strength back and started feeling better and better. I went back to work, and everything started getting back to normal again. I got back in my regular routine in my job as a wire bonder. I had always been the clown at work, so it took me a while to get back to joking again.

Today I can say I'm glad I went to the doctor, got help for myself, and saved my life. I don't have a baby today, but I feel I'm a better person. I've gone back to school, and I have good health and people who love me.

Handout #5: Facts About Breast and Cervical Cancer

- Breast cancer is the most common cancer among women.
- As women get older, their chances of getting breast cancer increase.
- The earlier breast cancer is found, the more treatment options a woman has and the better her chance for a cure.
- A mammogram is an x-ray of the breast. It can find breast cancer in its earliest stages, when it may be as small as a pencil point.
- Women age 50 and older should have a mammogram every year. All women should have yearly clinical breast exams, and all women should do monthly breast self-exams.
- All women are at risk of getting breast or cervical cancer, even if there is no family history.
- A Pap test is very quick and simple.
- Changes in the cervix (abnormal cells) can be treated before cancer develops.
- Women should have a Pap test every year. They should continue to have Pap tests throughout their life, even if they are done having children, no longer having periods, or not having intercourse.
- Nearly half of all women who die from cervical cancer are older than age 65. Older women at greatest risk are those who have not had regular Pap tests.

Handout #6:
Stages of Change Model
Stage 1: Precontemplation (Not Thinking About It)

Role of Community Health Workers

You should provide basic information about the health benefits of having the screenings, the risks of cancer, and the ability of screenings to find cancer when it is most easily treated.

A^{sk}

- What do you know about breast cancer, cervical cancer, mammograms, or Pap tests?
- Do you know that a mammogram can find a lump very early—earlier than your doctor could feel it?
- Do you know that a Pap test can find problems before they turn into cancer?

A^{dvice}

If a woman has never heard of a Pap test or mammogram, tell her about one or more of the following points. You will need to decide which points are best to address with each woman.

- Breast cancer is the most common cancer among women.
- As women get older, their chances of getting breast cancer increase.
- The earlier breast cancer is found, the more treatment options a woman has and the better her chance for a cure.
- All women are at risk of getting breast or cervical cancer, even if there is no family history.
- Nearly half of all women who die from cervical cancer are older than age 65. Older women at greatest risk are those who have not had regular Pap tests.
- Changes in the cervix (abnormal cells) can be treated before cancer develops.
- A mammogram is an x-ray of the breast. It can find breast cancer in its earliest stages, when it may be as small as a pencil point.
- Most professional societies agree that women age 50 and older should have a mammogram every year. All women should have yearly clinical breast exams, and all women should do monthly breast self-exams. Suggested frequency of screening for breast cancer for women ages 40 to 49 remains controversial. The American Cancer Society recommends that women ages 40 to 49 have a mammogram every 1 to 2 years and a clinical breast exam every year.

The National Cancer Institute recommends that women seek the advice of their doctors about what age to begin screening.

- You can ask if the woman has heard the story about (name of a well-known person) and how a mammogram found her cancer early.
- A Pap test is very quick and simple.
- Women should continue to have Pap tests throughout their life, even if they are done having children, no longer having periods, or not having intercourse.

Assist

You will decide what assistance you can provide.

- Give information on free or low-cost screening services.
- Give your name and phone number—or the name and phone number of someone in the breast and cervical cancer early detection program—so the woman can call if she has questions.

Adapted with permission from the following publications: (1) Prochaska, J.O.; DiClemente, C.C.; Norcross, J.C. In search of how people change: applications to addictive behaviors. *American Psychologist* 47(9): 1102-1114, 1992; (2) O'Donnell, J.F.; O'Donnell, L.; Jackson, R.; Dash, K.; Adler, M.; Carney, P.; Juhn, G.; Dana, A. Building partnerships for breast and cervical cancer risk management: a CME curriculum for physicians and other health care providers. Newton, MA: Education Development Center; 1997; and (3) Dubé, C.; Rosen, R.; Goldman, R.; Ehrich, B.; Toohey, H.; Rakowski, B.; Goldstein, N. Communication skills for breast and cervical cancer screening: a medical school curriculum. Providence, RI: Brown University; 1998. Permission for additional reproduction, beyond normal classroom use, must be obtained from the program or authors.

Handout #6:
Stages of Change Model (continued)
Stage 2: Contemplation (Thinking About It)

Role of Community Health Workers

You should emphasize the benefits associated with mammography or Pap tests. You should encourage a woman to have a mammogram or Pap test in the coming year.

A^{sk}

- Have you talked to your doctor or nurse about having a mammogram or Pap test?
- How do you think you would benefit from having a mammogram or Pap test?
- What are your fears about having a mammogram or Pap test?

A^{dvice}

Based on the woman's answers to the above questions, tell her about one or more of the following points. You will need to decide which points are best to address with each woman.

- The earlier breast cancer is found, the more treatment options a woman has and the better her chance for a cure.
- Changes in the cervix (abnormal cells) can be treated before cancer develops.
- A mammogram is an x-ray of the breast. It can find breast cancer in its earliest stages, when it may be as small as a pencil point.
- Women age 50 and older should have a mammogram every year. All women should have yearly clinical breast exams, and all women should do monthly breast self-exams.
- Community health workers can ask if the woman has heard the story about (name of a well-known person) and how a mammogram found her cancer early.
- A Pap test is very quick and simple.
- Most professional societies agree that women age 50 and older should have a mammogram every year. All women should have yearly clinical breast exams, and all women should do monthly breast self-exams. Suggested frequency of screening for breast cancer for women ages 40 to 49 remains controversial. The American Cancer Society recommends that women ages 40 to 49 have a mammogram every 1 to 2 years and a clinical breast exam every year. It recommends that women age 50 and older have a mammogram and a clinical breast exam every year. The National Cancer Institute recommends that women seek the advice of their doctors about what age to begin screening.

- Women should continue to have Pap tests throughout their life, even if they are done having children, no longer having periods, or not having intercourse.

Assist

- Use the brochure from the breast and cervical cancer early detection program to give information about program services.
- Offer to help schedule an appointment or provide the name and phone number of someone who can.
- Offer to provide information on transportation.
- Offer information about eligibility for free or low-cost screening services.
- Give your name and phone number or the name and phone number of someone in the breast and cervical cancer early detection program. Encourage the woman to call if she has questions.

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Handout #6:
Stages of Change Model (continued)
Stage 3: Preparation (Getting Ready for Action)

Role of Community Health Workers

You should provide the “how-to” information and identify, discuss, and reduce specific barriers.

A^{sk}

- Can you get time off from work to get the screening tests?
- Do you know anyone else who has had these screening tests recently? Would it help to talk to that person?

A^{dvice}

Based on the woman’s answers to the above questions, tell her about the following points.

- Family history of breast cancer and increasing age, especially being older than age 50, are the most important risk factors for breast cancer.
- Getting a mammogram is a little uncomfortable but not painful; appointments take less than 1 hour; and technicians usually are female and very nice.

A^{ssist}

You will decide what assistance they can provide.

- Offer the name and phone number of a breast and cervical cancer early detection program staff person who can schedule a screening appointment.
- Offer information about available transportation.
- Offer information about available child, elder, or spouse care.
- Help identify screening services offered during nonwork hours.

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**Handout #6:
Stages of Change Model (continued)
Stage 4: Action**

Role of Community Health Workers

You should reinforce a woman's decision and provide her with necessary details to enable her to get screened.

A^{sk}

- I think it is great that you have decided to get a mammogram. Do you have any questions about it?
- Would you like someone to go with you for support?

A^{dvice}

Based on the woman's answers to the above questions, tell her about one or more of the following points. You will need to decide which points are best to address with each woman.

- It is great that you have decided to have a Pap test; if found early, changes in the cervix (abnormal cells) can be treated before cancer develops.
- _____ can arrange for child, elder, or spousal care.
- Here is the phone number to call to find out if you can get free breast and cervical cancer screening tests:_____.
- Deciding to have a Pap test or mammogram is a great example of how well you take care of yourself.

A^{ssist}

Women in this stage of behavior change do not need assistance. They are taking action.

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**Handout #6:
Stages of Change Model (continued)
Stage 5: Maintenance**

Role of Community Health Workers

- You should reinforce the behavior for setting up the next mammogram or Pap test. You should emphasize the benefits the woman can expect to gain because of the behavior change. You should provide any practical “how-to” information.
- You should be caring, help the woman in relapse learn from her mistakes, offer support for screening tests taken in the past, and encourage her to make another appointment.

A^{sk}

- How can we make getting your mammogram or Pap test as easy for you as possible?
- What are your biggest concerns?
- [For women in relapse] That was terrific that you made the appointment. What made you change your mind about getting the mammogram (or Pap test)?

A^{dvice}

Based on the woman’s answers to the above questions, tell her about one or more of the following points. You will need to decide which points are best to address with each woman.

- If you do not have a lump, a mammogram can reassure you that there is no lump present; if a lump develops, regular mammograms will find it when it is very small.
- I am sure it means a lot to your family that you are taking such good care of yourself.
- The earlier breast cancer or cervical cancer is found, the more treatment options a woman has and the better her chance for a cure.
- Most experts agree that women age 50 and older should have a mammogram or Pap test every year. In addition, they recommend that women have a yearly clinical breast exam from their provider and do monthly breast self-exam.

A^{ssist}

You will decide what assistance you can provide.

- Use the breast and cervical cancer early detection program brochure to give the woman information about program services.

- Offer to schedule an appointment or give her the name and phone number of someone who can.
- Offer information about transportation.
- Offer information about eligibility for free or low-cost screening services.
- Give your name and phone number or the name and phone number of a staff member from the breast and cervical cancer early detection program. Encourage the woman to call if she has questions.

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